How to apply for a research permit in Health and Social Services

Helsinki

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Before you apply for a research permit

Health and social services require a research permit for all research, theses and reports in which data regarding the Division's customers, personnel or materials are collected.

Please read these application instructions carefully and fill in all the requested information on the electronic form. Verbal answers cannot be replaced by referring to sources. The processing time for research permits at health and social services ranges from 2 weeks to 1.5 months when the application has been filled in correctly. An incomplete application will delay the processing of the research permit. The person preparing the research permit will contact the applicant to ask for additional information, if necessary.

In this context, research refers to scientific research, bachelor's theses, various reports, pilots and other projects subject to research permits, in which data regarding the personnel or customers of health and social services is collected. Researcher refers to the person who implements the research and processes the data.

Before applying for a research permit, **please contact the unit in City of Helsinki health and social services in which you intend to carry out the research** to enquire if the research can be implemented. Agree on a **contact person** at the intended service or unit with whom you can agree on the practical arrangements of the study, such as data collection, recruitment of research subjects, as well as presenting the completed research report. You can look up persons in the city's phone directory. The completed research or its link must be sent to the contact person or to sotepe.tutkimusluvat@hel.fi.

In terms of its objectives, methods as well as its means of data collection and execution, the research must suit the health and social services' operations, as well as fulfil research ethics and privacy protection requirements. **You may only start recruiting research subjects and collecting data after you have been granted the permit.** If the research data is not collected before the expiration of the research permit, you must apply for a renewal permit with the same application form.

Before submitting your research permit application you must explain, in as much detail as possible, **which City of Helsinki's data you would like to use or which target group you would like to study.** The study and data collection should be carried out without unreasonable effort from the personnel. If the study is not suitable for the division in the applied format, the contact person can negotiate with the applicant to find methods or limitations that make the implementation of the study possible. In terms of theses, the educational institution's supervisor is responsible for the research-related supervision.

If the study is implemented in several services, you must have a separate contact person in each service. Also, if you are going to study the purchased services units' customers and family members, a contact person from the health and social services is also required – even if you are recruiting research subjects through the purchased service's staff.

Find out if your study needs an ethical review or a privacy protection impact assessment.

Attach the following to your research permit application:

- Research plan
- Information letter to the research subjects
- Material related to the data collection, such as a consent form, survey form, interview outline, description of the observation, or data request form for statistics
- Privacy policy, if you collect and process personal data
- Privacy protection impact assessment (if necessary)
- Statement from a research ethics committee (if necessary)

More information about the above attachments is available below in this document.

Electronic application form and application instructions

If you do not want to or cannot use strong identification, you can fill in the application form, convert it to PDF-form and send it with your signature to the City of Helsinki Register Office.

The instructions below are in the same order as the electronic application form.

Research permit applicant, other members of the research team, and research supervisor/director

Research permit applicant

As the main applicant, fill in your personal information on the form. Include an email address from which the person preparing the research permit can contact you for more information or for completion requests.

The data may only be processed by persons necessary for the research for research purposes. If the research team has more members or if the research data is processed by other persons than the main applicant, add their information under Other members of the research team.

Please note that the people processing personal data and confidential information must submit an attachment with their signature, date of signature and name in block letters in the last part of the form. If needed, one can use this signature form. All signatures must be handwritten or real electronic signatures. For example, a name typed in cursive is not a valid signature.

If new members join the research team or new people start processing the data later on, they must send their confidentiality agreement to the City of Helsinki Register Office along with the registration number of the research permit. You can find the registration number in the record extract of the research permit decision and, if necessary, by asking from sotepe.tutkimusluvat@hel.fi.

Research supervisor/director/approving officer

Information of the research supervisor or the one approving the research plan must be filled in when it comes to theses that are included to degrees. The supervisor must accept the thesis' research plan with their signature. If needed, one can use this signature form. For research projects, for instance, you can enter the research director's information, if it is someone other than the research permit applicant.

Research project

Research subject, objective and purpose

Explain the topic of study in further detail, if necessary. Explain the objective and purpose of the study.

A short description of the execution of the research

Explain the research frame, data collection and how the research subjects are recruited. Note that the researcher **may not contact potential research subjects directly**. Instead, any communication about the research and recruitment must happen, for example, through the contact person working at the target unit in health and social services, or through someone else in a manner agreed upon with the contact person. This ensures the voluntary nature of participation and prevents the researcher from collecting unnecessary personal data, such as names and email addresses.

Attach the research plan

Attach the research plan to your application. The plan should include the target group, research questions, the purpose and objectives of the study, research methods, data collection methods, data analysis, as well as data retention during the research as well as its deletion or storing.

The research plan must be ready when you apply for the research permit, which means that applying for the research permit is generally the last step before starting the data collection. The

research plan must explain in practical terms how customers or employees of Helsinki's health and social services are directed to the study or how and by whom the register data is collected and where it will be stored. If the research plan's text exceeds ten pages, you must also attach a summary that clearly explains the aforementioned aspects.

The research plan must give an overall picture of the research, but also specify the factors concerning and essential to the City of Helsinki's health and social services. This is important especially in studies that are also carried out in other organisations. The used terms should also match the terms used by the division. Any necessary details can be asked from the contact person in the target service.

Contact person(s) at the Social Services, Health Care and Rescue Services Division

Include contact details for the contact person at health and social services. You must have agreed upon the practical implementation of the study with the contact person before applying for the permit. If the research applies to several services, you must have a contact person in each service. A contact person at health and social services is also required if you are going to study customers or family members from the purchased services units, even if you are recruiting the research subjects through the purchased service's staff.

Application for an extension or change to an existing permit

If this is an application for an extension or change to an existing permit, include the registration number of the original research permit and the date it was granted. You can find it in the record extract of the decision sent to you. Also, explain what the extension or change concerns. For example, are you applying for an extension to the data collection time, or has the research frame changed and you want to extend your data collection to a new target? Ask your contact person for their opinion of extending your data collection beforehand. Fill in the applicable parts of the application. Attach all necessary documents along with confidentiality agreements signed by the persons processing the data. You do not need to send again the original research plan or attachments related to the earlier application. If you want to check whether you need a new permit or not, please contact sotepe.tutkimusluvat@hel.fi.

Research area within the Social Services, Health Care and Rescue Services Division

Select the services in which the study will be implemented / from which data will be collected. Also, specify the units/teams in the selected services in which you want to carry out your study or from which data will be collected. Verify the implementation location with your contact person. You can examine the organisation on the City of Helsinki website.

Data collection methods

Select the methods used to collect data at Helsinki's health and social services.

Targets for minimum and maximum sample sizes

Explain the intended size of your sample, for example, how many interviews do you want to implement or for how many people will the survey be sent to, and what is your desired response rate?

Materials related to data collection

Select the documents related to the research frame. The material will be attached in the following section of the form or as an attachment to the research plan.

- **Research information sheet** to the study subjects written in easy-to-read language and in a way that the target group can understand. It must include:
    - A short description of the study, its purpose and how the participant was selected to the study.
    - How the participant's data will be protected and how is it ensured that the data is processed and presented in all phases so that individual data is not revealed. (Privacy protection issues should be explained in more detail in the privacy policy.)
    - Duration of the study.
    - How the results will be reported and published.
- **Consent form** for study participants, dated and signed by the main applicant.
- **Questionnaire/survey form**. Include the questions you intend to ask the participants.
- **Interview outline**, i.e. the interview questions or themes of a theme interview.
- **Description of observational methods**, i.e. how will the observation take place, who and what is observed, how will the voluntary nature of participation be ensured and what kind of data is collected?

A voluntary consent is requested from the participants after the research permit is admitted, and before the data collection. The consent must be requested in writing when the data is collected through, for example, interviews, workshops, or observation. It will be signed by both the participant (the person giving the consent) and the recipient (generally, the researcher). A copy must be given to the person giving their consent. Please note that just by collecting the consents in writing, you are collecting personal data. This means that you must have a privacy policy regarding the processing of personal data that is attached to the application.

In survey studies, consent may be requested at the beginning of the survey with a section confirming the participant's active consent with, for example, a checkbox. This way, the consent

can be verified later. In connection with the consent, it must be shown that the participant has had a chance to read the research information sheet and privacy policy, as well as e.g.:

- How the participant's contact details were obtained.
- What data will be collected from the research subjects.
- Who will process the data.
- What will happen to the research register after the study.
- The participant's right to refuse and leave the study at any point without it having a detrimental impact for instance on the client relationship or access to services. The participant must also know who they can notify of their refusal.

Intended time period of data collection

Include the time period during which data will be collected at the City of Helsinki's health and social services. As you are choosing the start date, please note that the data collection can only begin once the research permit has been granted.

Research ethics and costs incurred by the Division

Research ethics

Describe how ethical aspects are considered in the study. The research process must follow general principles of research ethics. The participants must be informed of the study, their rights, and the processing of their personal data. Participation must be voluntary, and the participants must be asked for their informed, active and verifiable consent. It must not be possible to identify any study participants from the research report or other publications made from the study.

Select if the study needs a research ethics committee's statement, or some other ethical assessment. An ethical review is generally necessary when data is collected from customers or patients of health and social services, or when it is a medical study. If the study requires an ethical review, you must apply for it before applying for the research permit and starting your study. Attach it to your application.

In medical studies (the Finnish Medical Research Act 488/1999), you need to obtain an opinion from the HUS Ethics Committee or the National Committee on Medical Research Ethics. In other than medical studies, you need to obtain an opinion from some other ethics committee. In drug trials, you need to obtain a statement from the Finnish Medicines Agency (FIMEA).

Ethical statements are not generally given for undergraduate students (bachelors' theses), as they are meant for research work carried out after it.

Cost incurred by the Social Services, Health Care and Rescue Services Division

Estimate the necessary personnel resources and other costs together with your contact person.

In register studies, contact statistics services (sotepe.tilastoneuvonta@hel.fi) to enquire about the availability of data, sampling, and costs before submitting your application.

Description of the personnel's contribution (including an estimate of the necessary working hours): Itemise the time spent on participating in the study per person, including, for example, the time spent for the interview.

Financier(s): If your research has or will have financiers, include their names.

Access rights, documentary data, study register and impact assessment

Access rights

If you have applied or will apply for access rights to an information system of the social services, health care and rescue services for your research, to which system and for which time period? Find out about the necessary access rights and systems with your contact person.

Documentary data that access is applied for

Required confidential documentary data related to health and social services: In as much detail as possible, name the systems you want to use and describe the data you want to search for. Discuss with your contact person if it is possible to collect the data.

Processing of personally identifiable information

Does the research involve the processing of personal data?

Nearly in all studies at health and social services personal data is processed – even when the purpose is not to collect personal data.

Personal data can be any data from which a person can be identified. Direct personal data are, for example, **email address, name in a consent form, and a voice recording of an interview**. Indirect personal data are information that, when combined, it might be possible to identify a person. These include e.g. **age, gender, education, profession, place of work, or a client relationship with a certain service**.

If, for example, your survey form has **fields for open-ended answers,** and your purpose is not to collect personal data, you must clearly ask the participants not to share data from which they or someone else can be identified. However, the researcher must take into account that the respondent may share identifiable data in the open-ended answer fields, so you must also tell

the participant how the data will be processed in such a case by, for example, anonymising or deleting the identifier.

As you carry out your impact assessment, please note that anonymising research data is generally difficult in practice. Data is anonymous only if no one can identify a person from it even indirectly. When anonymising research data, all data related to a natural person, based on which the person can be directly or indirectly identified, is irrevocably removed. An example of anonymous data is aggregated statistical data, which refers to statistical, reliably anonymised data.

Read the requirements set for your research by the Finnish Data Protection Act (1050/2018) as well as your organisation's instructions regarding the privacy protection of research. More information is available on the Data Protection Ombudsman's website.

The processing of personal data refers to all operations targeted at personal data, such as collecting, saving, organising, structuring, storing, modifying, moving, searching for, requesting, using, disclosing through transfer, transmitting, or otherwise making accessible, combining, restricting, deleting, and destroying data. Viewing data also counts as using it and, thus, processing, in which case the legislative requirements regarding the processing of personal data must be considered.

When processing personal data, a privacy statement must be attached to the application. You can ask your educational institution or organisation for a template. The privacy statement must include the following information:

- Data controller's name and contact details (generally, the researcher or their organisation)
- Name of the study
- Party responsible for the study with contact details
- The basis for processing personal data – usually consent, or public interest and public authority
- Purpose, duration and implementation of the study
- Kinds of personal data collected and reasons for collecting them
- How the personal data will be protected
- Participants' rights
- Notice about whether personal data will be disclosed to third parties
- How personal data is stored, will it be destroyed after the study ends, and how

Impact assessment

Justify why you are asking for personal data, why for this particular personal data, and why in the selected extent. All collected personal data must be justified, and you cannot collect any unnecessary data. Also, describe the risks to the participants' rights and freedoms at the

different phases of the study and data collection, as well as the measures with which the risks are to be minimised.

Data protection impact assessment

A data protection impact assessment must be carried out

- **in general**, when data from customers of social services and health care are collected
- **always**, when the data controller processes special categories of personal data, such as health data, genetic or biometric data, sexual orientation data, and wishes to derogate from certain rights of the data subject. The rights include rectification of data, erasure of data, restricting the processing of data, and the right to object to the processing of data. In addition, in this case, the impact assessment must be submitted in writing to the Data Protection Ombudsman before starting the processing.

In accordance with the Office of the Data Protection Ombudsman, an impact assessment is mandatory when the planned processing may cause a serious risk to people's rights and freedoms. In scientific research, processing will often incur a high risk, so an impact assessment must be carried out. An impact assessment must be carried out, for example, when two or more of the below conditions are fulfilled:

- The processing concerns special categories of personal data or otherwise very intimate data.
- The processing of personal data is done on a large scale.
- Data sets are combined.
- The processing concerns vulnerable individuals, which can be minors, immigrants, or incapacitated subjects.
- The processing involves application or innovative use of new technical or organisational solutions.
- The processing concerns biometric data.
- The processing concerns genetic data.
- The processing concerns geographical positioning data.
- You want to deviate from informing the data subject on the basis of Article 14(5), point b of the General Data Protection Regulation.
- You want to derogate from other rights of the data subject.

The purpose of the impact assessment is to **help you identify risks related to the processing of personal data, to assess their seriousness, as well as to control them.** The impact assessment is meant to be a continuous process of risk identification and management. It describes the **processing of personal data, assesses the necessity and proportionality of and risks created by the processing, as well as the necessary measures with which the risks will be dealt with**.

The objective of the impact assessment is to **assess whether the remaining risk is justified and acceptable under the conditions in question**. The impact assessment helps the data controller to comply with the requirements of data protection legislation as well as to document and demonstrate it. (tietosuoja.fi/en/impact-assessments) Generally, the data controller is the researcher/person applying for the research permit.

Read more at the Data Protection Ombudsman's website.

If the conditions for completing an impact assessment referred to in Section 31 of the Data Protection Act are not fulfilled, the person preparing the permit can, if necessary, ask the applicant to fill in the privacy protection checklist to obtain the research permit.

Retention and disposal of the research data

Describe the secure storing of the data and disposal or archival of the research material.

Checklist of the required attachments

In the research permit application, you need to attach the research plan as well as all other material required to collect data. Make sure that all necessary attachments are included before sending the application. At this point, you can still add attachments that you have not yet attached or were not able to attach earlier. If necessary, any missing attachments can be submitted to the City of Helsinki Register Office after submitting the application.

Confidentiality agreements and signatures of the research permit applicant and research team

Everyone who processes data included in confidential documents or personal data registers must sign a confidentiality agreement. The main applicant of the research permit signs the application and confidentiality agreement with strong electronic identification. The other members of the research team shall sign confidentiality agreements with the same content, and submit them as a separate attachment. The confidentiality agreements refer to the confidentiality and secrecy obligation regarding data received in connection with the research.

If needed, one can use this signature form.

Additional information

If necessary, you can share any additional information regarding the research permit application here. If you have questions, you can ask for more information by emailing sotepe.tutkimusluvat@hel.fi.

Helsinki

City of Helsinki
Social Services, Health Care and Rescue Services Division

Toinen linja 4 A
FI-00530 Helsinki
PO Box 6008
FI-00099 City of Helsinki

www.hel.fi